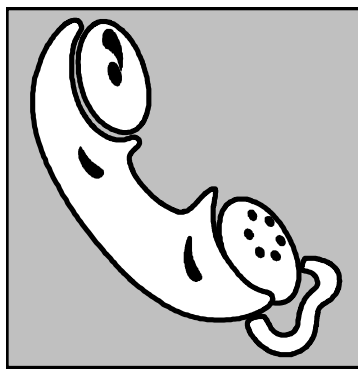


**Special Medical Services Bureau**

**INFORMATION AND REFERRAL**

**2004 REPORT**



New Hampshire Department of Health and Human Services  
Office of Medicaid Business and Policy  
Bureau of Medical Services  
Special Medical Services

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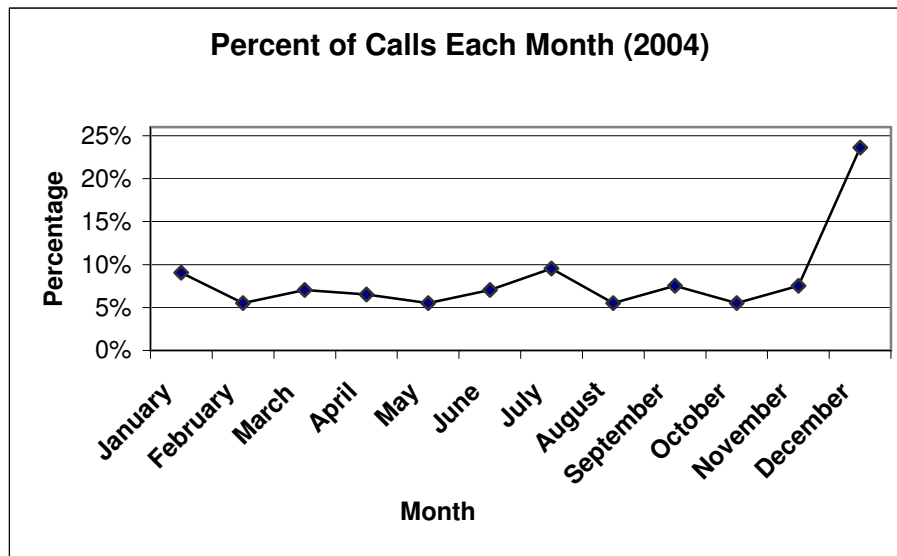
## Information and Referral Report for 2004

The Special Medical Services (SMS) public help line<sup>1</sup> received 199 telephone inquiries about health-related subjects and concerns during calendar year 2004. Information and referral is the first level in the nationally recognized 4-tiered care coordination model utilized by the New Hampshire Title V program for Children with Special Health Care Needs. (Table 1 and Figure 1)

**Table 1**

Calls Per Month (2004)		
Month	Frequency	Percent
January	18	9%
February	11	6%
March	14	7%
April	13	7%
May	11	6%
June	14	7%
July	19	10%
August	11	6%
September	15	8%
October	11	6%
November	15	8%
December	47	24%
Totals	199	100%

**Figure 1**



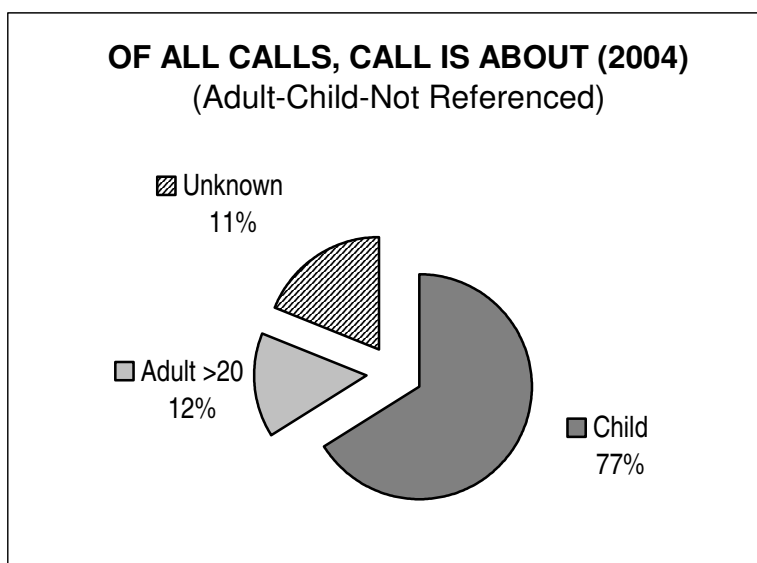
<sup>1</sup> Special Medical Services staff handled the line. The counts do not include calls to the New Hampshire Family Voices (NHFV) 1-800 number, also funded by Special Medical Services, as NHFV collects and reports that data separately. The count also does not include calls handled by Upper Valley Support Group, as there was no contract with that organization during SFY 05.

Of 176 calls where the reference was identified, 87% of the calls were about a child (n=153) and 13% (n=23) were in reference to an adult (n=66). Of all calls, 77% were about children. (Table 2 and Figure 2)

**Table 2**

Call is About (2004)	Frequency	Percent
Child	153	87%
Adult >20	23	13%
Total referenced calls	176	100%

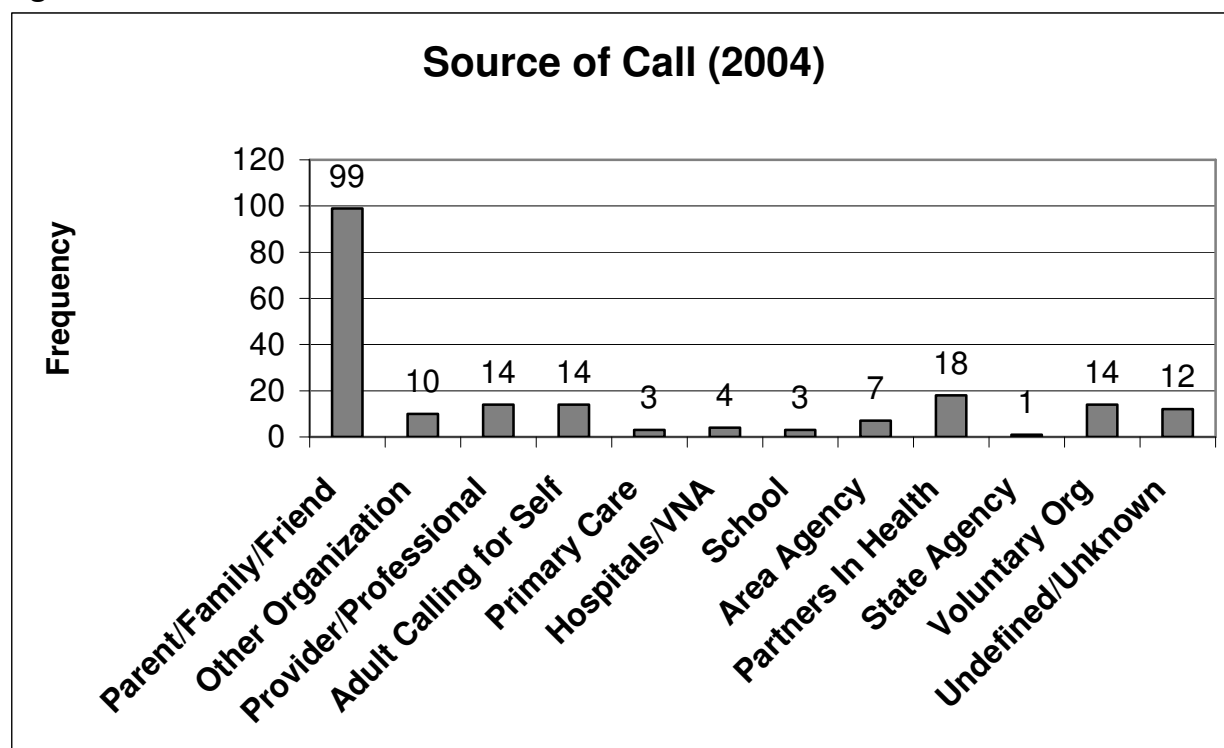
**Figure 2**



Half (50%) of the inquiries were from parents or friends. Nine percent (9%) of calls came from Partners in Health, a statewide program that provides support for families of children with chronic illness. Seven percent (7%) of calls came from other voluntary organizations and 7% came from adults calling for themselves. Providers and professionals made up another 7% of inquiries. The “unknown/undefined” categories of callers comprised 6% of the calls. Five percent (5%) of calls came from hospitals, schools and primary care practices and another 5% came from other organizations. Four percent (4%) of calls came from area agencies and other State agencies. (Table 3 and Figure 3)

**Table 3**

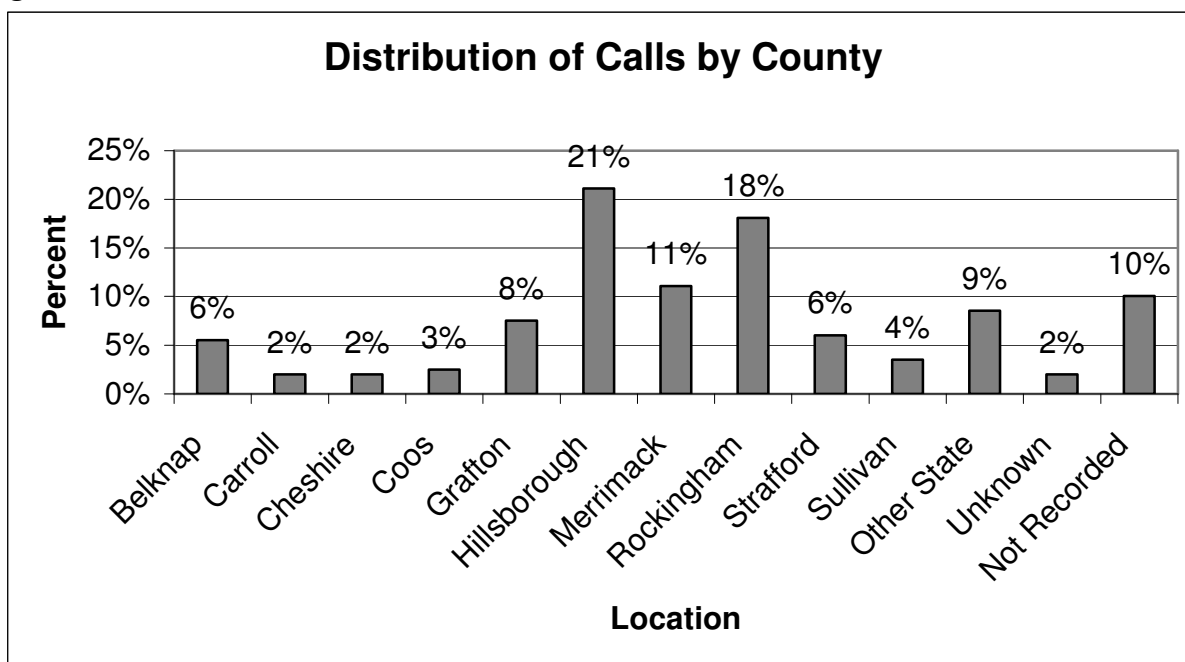
<b>Calling Source (2004)</b>	<b>Frequency</b>	<b>Percent</b>
Parent/Family /Friend	99	50%
Other Organization	10	5%
Provider/Professional	14	7%
Adult Calling for Self	14	7%
Primary Care	3	2%
Hospitals/Visiting Nurses Association	4	2%
School	3	2%
Area Agency/Parent to Parent	7	4%
Partners in Health	18	9%
State Agency	1	1%
Voluntary Organization	14	7%
Undefined/Unknown	12	6%
Total	199	100%

**Figure 3**

Calls were received from all ten New Hampshire counties, and were congruent in ratio with the distribution of the state's population, per the 2000 Census. (Table 4 and Figure 4)

**Table 4**

<b>Calls by County (2004)</b>	<b>Frequency</b>	<b>Percent</b>
Belknap	11	6%
Carroll	4	2%
Cheshire	4	2%
Coos	5	3%
Grafton	15	8%
Hillsborough	42	21%
Merrimack	22	11%
Rockingham	36	18%
Strafford	12	6%
Sullivan	7	4%
Other State	17	9%
Unknown	4	2%
Not recorded	20	10%
Total	199	100%

**Figure 4**

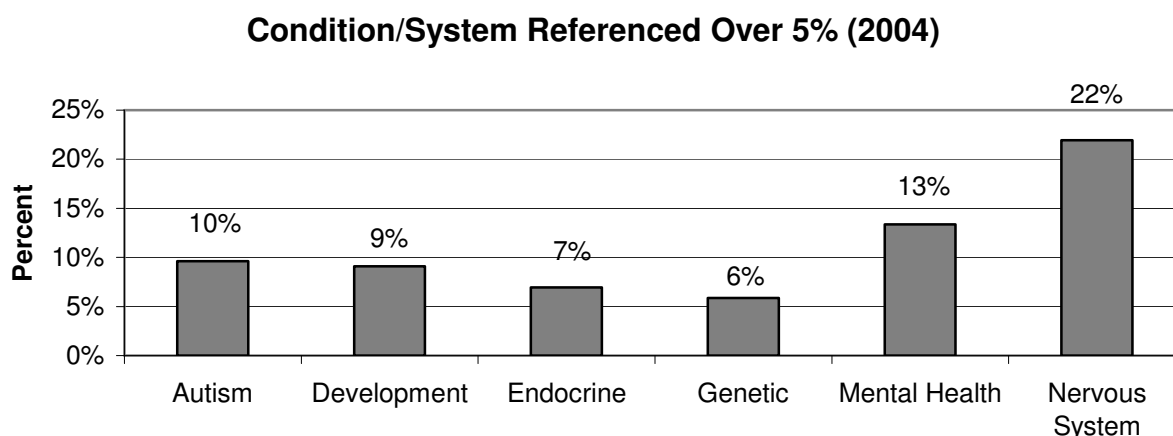
The conditions and/or body systems that callers referenced covered a wide range of medical diagnoses and health-related areas. The calls were divided into broad categories, which include the numerous specific conditions referenced by the callers. (Table 5)

**Table 5**

<b>Condition/System (2004)</b>	<b>Number</b>	<b>Percent</b>
Allergies	1	1%
Autism	18	10%
Cardiac	7	4%
Development	17	9%
Endocrine/Metabolic	13	7%
Gastro-Intestinal/Genito-Urinary	8	4%
Genetic/Birth Defects	11	6%
Health Conditions: Uncategorized	9	5%
Hearing/Vision	10	5%
Hematological	1	1%
Infectious Disease	3	2%
Mental/Behavioral Health	25	13%
Musculoskeletal	6	3%
Neoplasms	3	2%
Nervous System/Brain	41	22%
Not Directly A Health Issue (Ex. Medical Bills)	8	4%
Respiratory/Circulatory	6	3%
Total	187	100%

Six (6) conditions/body systems were each referenced in over 5% of the total calls. Twenty-two percent (22%) of calls were related to inquiries about conditions of the nervous system/brain, primarily cerebral palsy, seizure disorders, and learning disorders. Thirteen percent (13%) of calls referenced mental health issues and disorders, primarily attention deficit disorders and mental illness. Ten percent (10%) of calls referenced autism and autism spectrum disorders. Nine percent (9%) of calls referenced concerns about development and developmental delay. Seven percent (7%) of the calls that specified condition referenced endocrine/metabolic concerns, primarily diabetes and obesity. Six percent (6%) of the calls that specified conditions referenced genetic defects, primarily cleft lip and palate. (Figure 5)

**Figure 5**



Caller concerns are categorized into seven (7) broad themes: Health, Support, School, Literature, Respite, Basic Needs and Other/Information. Approximately thirty sub-topics are included within the main themes. Approximately 18% of calls reference multiple concerns and are categorized in multiple themes; therefore the number of concerns at 100% (n=245) exceeds the number of single calls at 100% (n=199).

- § **Health** generally relates to finding and accessing primary and specialty services, or technical assistance, for a wide variety of conditions, including oral health and mental health, or special diets, or procuring equipment and supplies. Financial concerns generally relate to Medicaid, insurance, SSI, money for medical bills or assistance with accessing services.
- § **Support** generally includes listening to parents, counseling, finding self-help groups, sibling support, or supports related to parenting, divorce, single parenting, step-parenting, custody, and so on. Parent matches are requests to link one family with another family for the purposes of support. Agency connections include linking consumers and/or professionals with local, state, or national resources.
- § **School** requests generally relate to help with advocacy for specific school programs or services, transition to school, transition to post-school, special education issues, or job training opportunities.
- § **Literature** generally includes requests for specific publications, lending library books, condition-specific information, for parents, professionals, or students in secondary and post-secondary schools. It also includes requests for agency informational brochures.
- § **Respite** generally relates to concerns about daycare, recreation issues, or home health care.



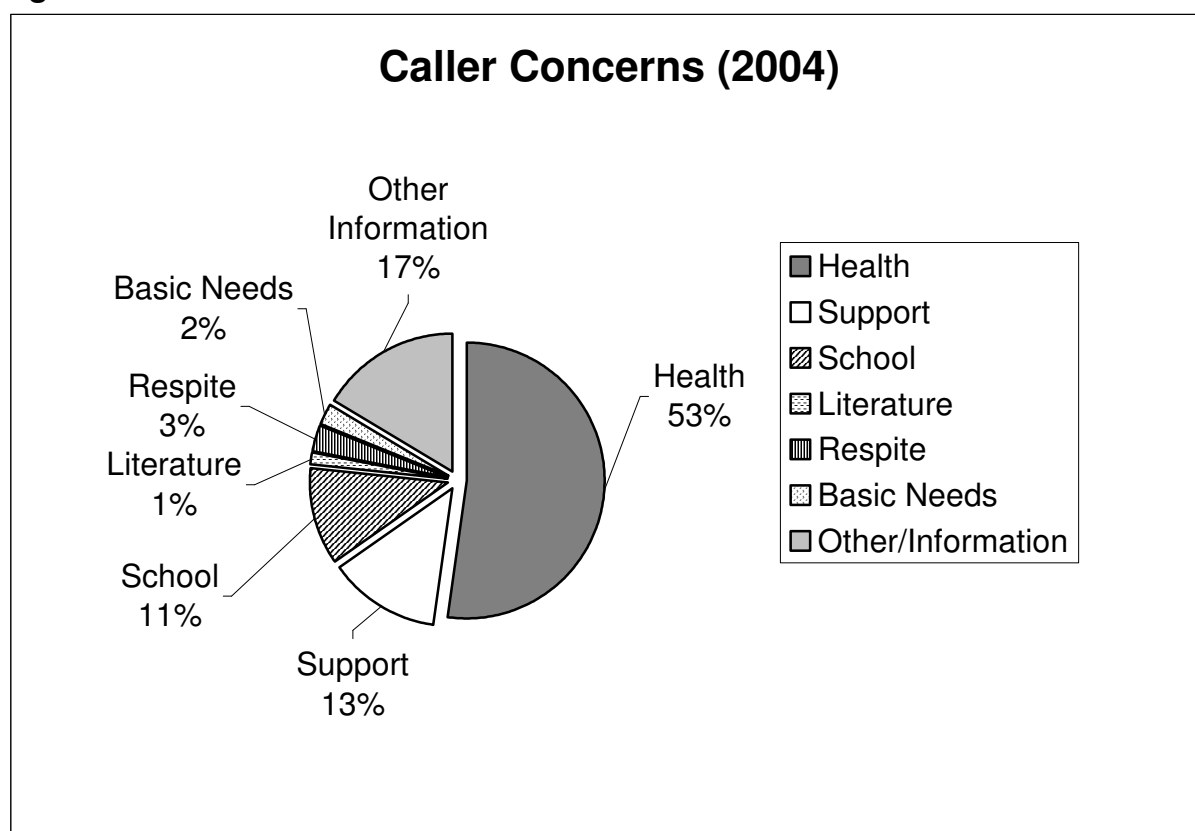
- § **Basic Needs** generally relates to inquiries regarding food, shelter, clothing, and transportation.
- § **Other information** generally includes requests for information not classified elsewhere, or concerns about issues not otherwise categorized, such as adoption, disability-related advocacy, training needs, or legal assistance.

**Table 6**

<b>Caller Concerns (2004)</b>	<b>Number</b>	<b>Percent</b>
<b>Health</b>	<b>128</b>	<b>52%</b>
Insurance, Costs, Medicaid, SSI	42	17%
Specialty Care/Management/TA	38	16%
Supplies/Equip/Meds/Spec. Diets	19	8%
Primary Care	3	1%
Dental Care	1	0%
Mental Health/Counseling	25	10%
<b>Support</b>	<b>32</b>	<b>13%</b>
Parent Match	9	4%
General Parenting	3	0%
Agency Connection/Group	20	8%
<b>School</b>	<b>28</b>	<b>11%</b>
Special Ed./Ed. Concerns/Transition	28	11%
<b>Literature</b>	<b>3</b>	<b>1%</b>
On Condition/Agency Brochure	3	1%
<b>Respite</b>	<b>8</b>	<b>3%</b>
Daycare/Recreation	8	3%
<b>Basic Needs</b>	<b>6</b>	<b>3%</b>
Food/Housing/Clothing/Transport.	6	3%
<b>Other Information</b>	<b>40</b>	<b>16%</b>
Miscellaneous	0	0%
Information	40	16%
<b>Total</b>	<b>245</b>	<b>100%</b>

The Health category made up over 50% of caller concerns. The highest frequency concerns referenced included financial issues such as health costs, Medicaid, SSI and insurance, at 17% of all calls and 15% of all calls were related to specialty care and technical assistance. The category for Other Information (not otherwise categorized) made up 16% of calls. Calls regarding the Support category comprised 13% of calls and issues related to the School category, such as special education and transition made up 11% of calls. In 2004 the category labeled “miscellaneous” was collapsed into the general category for “information”. (Figure 6)

**Figure 6**

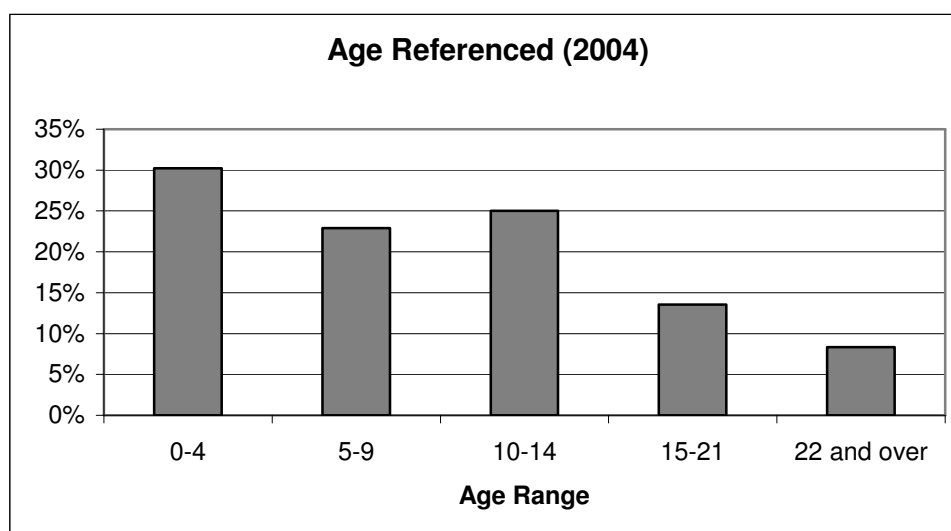


Callers reported the age of the person they were calling about in 48% (n=96) of the total calls. Nearly one third of the calls that noted age concerned children from birth to age 4. Over 20% referenced the 5-9 age group and 25% were in reference to children between the ages of 10 through 14. Young adults ages 15 through 21 were the focus of concern for 14% of calls and adults age 22 and over made up the remaining 8% of calls where age was disclosed. (Table 7 and Figure 7)

**Table 7**

Age Referenced	2004	
	Number	Percent
0-4	29	30%
5-9	22	23%
10-14	24	25%
15-21	13	14%
22-over	8	8%
Total	96	100%

**Figure 7**



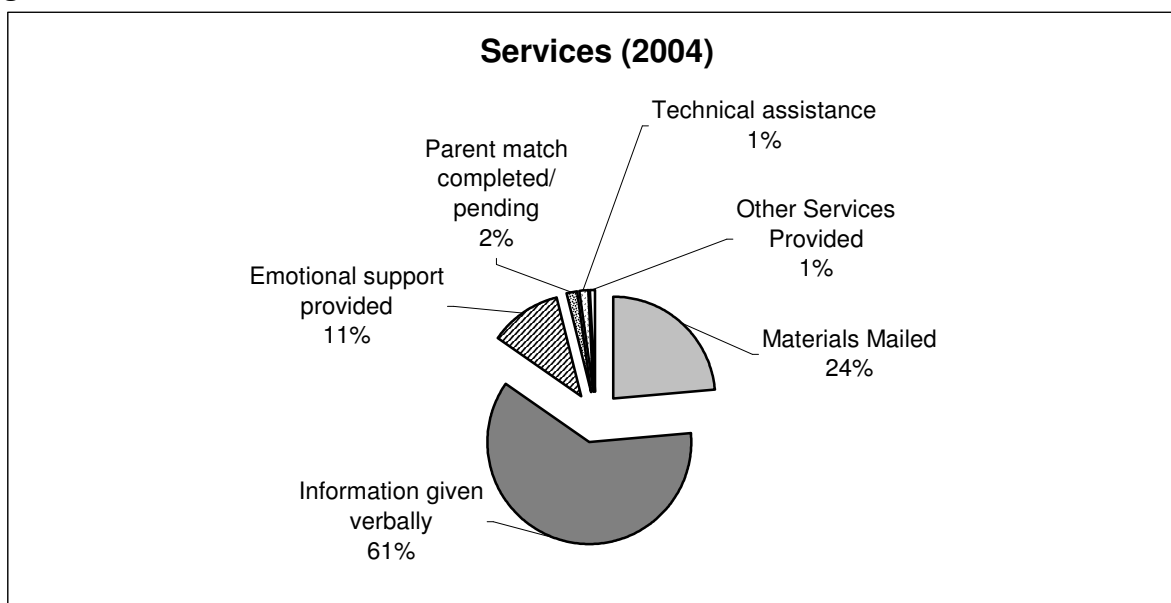
Inquiries for information and referral primarily come from family members of children with special health care needs, medical and service providers, professionals and interested others. The services rendered are clustered into six (6) broad categories.

- § **Mailed Materials** generally refers to the provision of literature, written correspondence (including e-mail), and the mailing of applications.
- § **Verbal Information** generally refers to telephone communications about any topics, conditions or services.
- § **Emotional Support** generally refers to empathic listening and problem solving.
- § **Parent Matching** refers to linking a parent with another parent for ongoing support and information. The Parent to Parent Upper Valley Support Group provides this service under contract with SMS.
- § **Technical Assistance** generally refers to the provision of consultation, or assistance in the area of advocacy, or with coordinating meetings or groups.
- § **Other/unknown** refers to services not captured by the other categories, or not reported.

Inquires for verbal information, and concerns resolved with verbal communication comprised about two-thirds of all calls. Materials mailed, or e-mailed, constituted the next largest service category, at 24%. Emotional support was provided as the identified service in 11% of the calls. (Table 8 and Figure 8)

**Table 8**

Service (2004)	Number	Percent
Mailed Materials	54	24%
Verbal Information	139	61%
Emotional Support	26	11%
Parent Matching	4	2%
Technical Assistance	3	1%
Other/unknown	2	1%
Total	228	100%

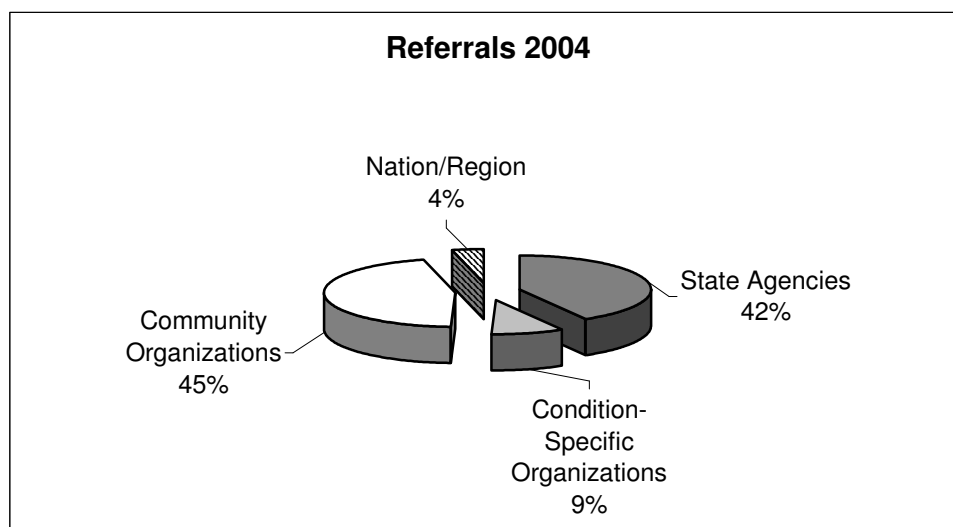
**Figure 8**

The information and referral system received 199 calls and made 250 referrals to a wide variety of agencies, services and organizations. Over 45% of referrals were to community-based organizations, comprised of parent groups, health care providers, specialty providers, local town services, area agencies, and other local resources. New Hampshire government agencies accounted for 42 % of the referrals. State offices include welfare district offices, the Social Security Administration, the Department of Education, Maternal and Child Health/WIC, Medicaid/Medicare, and the Division of Children, Youth and Families, among many others. Twenty-one percent (21%) of the referrals in this category were to the State Title V program for CSHCN, the Special Medical Services Bureau. (Table 9 and Figure 9)

**Table 9**

<b>Referrals (2004)</b>	<b>Number</b>	<b>Percent</b>
<b>State Agencies</b>		
Special Medical Services Bureau	52	21%
Welfare Office	9	4%
Social Security Administration	1	0%
Parentline	1	0%
Library (Family Resource Connection)	3	1%
Other State Offices	41	16%
<b>Total</b>	<b>107</b>	<b>42%</b>
<b>Condition-Specific Organizations</b>		
Parent Information Center	6	2%
Granite State Independent Living	3	1%
The Gregg Foundation	7	3%
Other condition specific org	7	3%
<b>Total</b>	<b>23</b>	<b>9%</b>
<b>Community Organizations</b>		
Town welfare	2	0%
Local health care	9	4%
Specialty providers	12	5%
Mental health providers	13	5%
Early Intervention	4	2%
Special Education/School	8	3%
Parent to Parent/Area Agency	7	3%
Partners in Health	20	8%
Other parent organizations	7	3%
Other community organizations	29	12%
<b>Total</b>	<b>111</b>	<b>46%</b>
<b>Nation/Region</b>	9	4%
<b>Total</b>	<b>9</b>	<b>4%</b>
<b>Total of All Referrals</b>	<b>250</b>	<b>100%</b>

**Figure 9**

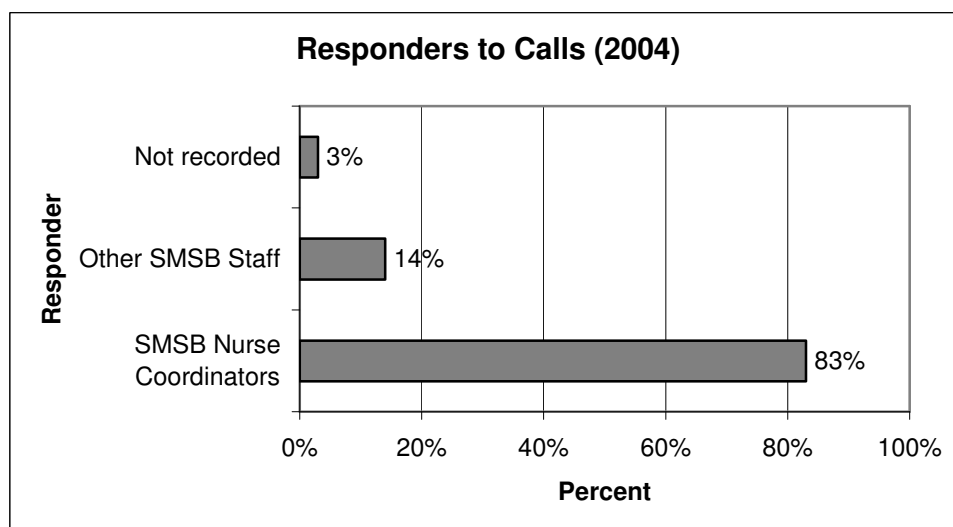


Personnel responding to information and referral inquiries include trained staff of the Special Medical Services Bureau. (Table 10 and Figure 10)

**Table 10**

Responder (2004)	Number	Percent
SMS Nurse Coordinators	166	83%
Other SMS Staff	28	14%
Not recorded	5	3%
Total	199	100%

**Figure 10**



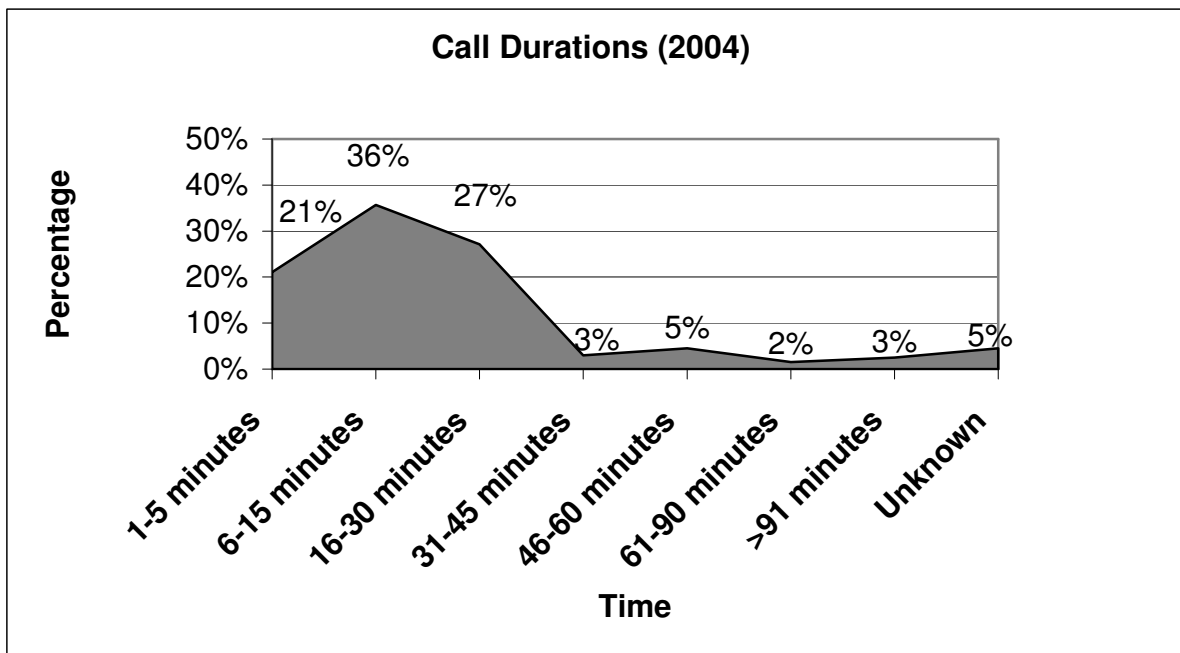
The length of time responders spent on calls to the information and referral lines ranged from 1-5 minutes to over one hour and a half. (Table 11)

**Table 11**

Telephone Time (2004)	Number	Percent
1-5 minutes	42	21%
6-15 minutes	71	35%
16-30 minutes	54	27%
31-45 minutes	6	3%
46-60 minutes	9	5%
61-90 minutes	3	2%
91 minutes and over	5	3%
Not recorded	9	5%
Total	199	100%

The majority of calls took 6-15 minutes to complete. Twenty-seven percent (27%) of calls involved up to 30 minutes. Five percent (5%) of calls involved a response time of up to one hour. (Figure 11)

**Figure 11**



The number of calls to SMS for Information and Referral continues a steady downward trend, from 1,069 in 1995 to 199 in 2004. This is partially a result of transitioning direct care services to the private sector. However, it is mainly due to contracting with external community-based organizations to provide Information and Referral to consumers, via telephone and web sites. These organizations fill a major role in Level I of the care coordination model used by SMS.

Historically, there have been two contractors: Upper Valley Support Group (UVSG) and New Hampshire Family Voices (NHFV). Upper Valley Support Group data was included in the SMS

counts up until the calendar 2004 report and will be resumed in SFY 05. In calendar 03, UVSG handled 234 (52%) of the 447 calls logged by SMS for the 03 report. The UVSG website (parent to Parent) logged an average of 28 hits daily, or about 10,300 for the reporting period of calendar 03.<sup>2</sup> Family Voices provides their call data in a separate Annual Report, which encompasses reports on other services within the contract with SMS. In SFY 04, Family Voices received 961 calls from parents and professionals, which is an increase of 111 over FY 03. Inquiries pertained to personal support, information, resources, ideas, and explanations regarding systems, guidelines, eligibility, requirements, rules and contacts. The NHFV web site averaged 250 hits a day, or over 29,700 for the reporting period. This is a 25% increase over FY 03.<sup>3</sup>

When NHFV information and referral calls are combined with calls received on the SMS public help line, the total equals 1,160, which is comparable to the volume of calls received in 1995.

To date, the Information and Referral Report has been prepared on a calendar year basis. Beginning with State fiscal year (SFY) 2005, Special Medical Services will convert to fiscal year reporting. In addition to reporting the calls coming directly in to the State phone line, SMS will be reporting on web-based inquiries from the State site. During calendar 04, ten e-mail requests for information and referral were handled, and the number is expected to steadily increase. Web-based methodology was only initiated by the State within the past two years. A reporting mechanism has not yet been programmed into the SMS database for these contacts, but an upgraded database is expected to be operational for the FY 05 report.

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<sup>2</sup> Totals for 2004 do not include calls to the Parent To Parent Upper Valley Support Group (UVSG), as in the past. The contract with UVSG was not funded for 2004, due to budget constraints. As such, comparisons are not being made with the 2003 data, which included UVSG calls, although previous years' data is included where available.

<sup>3</sup> NH Family Voices Family to Family Health Information and Resource Project, Annual Report, July 2003-June 2004